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ORIGINAL PAPER

Palliative care for children and adolescents in Switzerland: a needs analysis across three diagnostic groups

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Abstract The objective of this qualitative study was to explore the perceptions and needs of families who care for a child with a life-limiting disease. Considering the heterogeneity of life-limiting diseases in childhood, three diagnostic groups were defined: (a) cancer, (b) neurological disorders, and (c) non-cancer/non-neurological conditions. Fifteen parents whose child had been treated in one of four children's hospitals and received palliative care or had died within the previous 2 years were interviewed. The main interview topics were: communication with professionals, need for support in care (at home or hospital), and bereavement support. Irrespective of the center of care, parents of children with diagnoses other than cancer reported a lack of support concerning practical issues of care and psychosocial aspects. Parents of children with cancer expressed difficulties related to coordination of care especially when care was provided at home. Bereaved parents emphasized their wish for bereavement support. Our findings demonstrate shortcomings in pediatric palliative care in Switzerland and outline basic needs of affected families including psychosocial support, coordination of care and bereavement support. Based on these findings we formulate some suggestions on how to initiate pediatric palliative care in a most efficient way and tailored to the needs of families in Switzerland.

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Introduction

The impact of life-limiting disease in childhood is tremendous for the child and for the family [14, 15]. Pediatric palliative care (PPC) aims to improve the quality of life of these children and their families by reducing physical, psychosocial, and spiritual suffering [1, 28]. To achieve this goal, needs of these children and their families need to be identified. Recent review articles examining the needs of affected families revealed six domains critical to high quality PPC: (1) support of the family, (2) communication with child and family, (3) ethics and decision-making, (4) relief of pain and other symptoms, (5) continuity of care, and (6) grief and bereavement support [11, 17, 26].

Potential beneficiaries of PPC services are children with complex chronic conditions, especially those children whose conditions are progressive such as cancer, neurological diseases, cardiac, or metabolic disorders [6]. However, studies concerning PPC often include only one diagnostic group, mainly cancer [12, 16, 18, 23, 29], and may, therefore, not differentiate between the needs of families affected by children with different diseases. There is a paucity of research concerning PPC for children with neurological or metabolic diseases [5, 7, 25]. These children represent a challenging population for PPC, because their diseases tend to follow a protracted, undulating, and unpredictable course [10].

The primary goal of the present study was to define needs of Swiss families caring for a child with a life-limiting disease and to propose first activities a private

organization could launch to alleviate the suffering of these families. The secondary goal was to identify different needs between diagnostic groups. We used an interview guideline with open-ended questions to explore and to describe the needs of chronically ill children and their parents. This assessment was exploratory and descriptive in nature.

Methods

Setting and participants

The present study was part of a larger project that included additional interviews with 23 healthcare providers (physicians, nurses, socials workers, and psychologists). The results presented here pertain to the parents' perspective.

To achieve a most holistic view and in-depth understanding of the experiences, perspectives and needs of families with a child suffering from a life-limiting disease a qualitative study method was chosen. This approach is reasonable for an exploratory study of a so far understudied area within pediatrics.

Parents of children with life-limiting diseases who received treatment at one of four children's hospitals in Switzerland (Aarau, Lucerne, St. Gallen, and Zurich) were recruited. The local ethic committees approved all study procedures. The selection of participants was criterion based and purposive. Parents were considered for inclusion in this study if their child fulfilled the following four criteria: (1) it suffered from a life-limiting disease and received palliative care at the time of data collecting; (2) the disease was progressive with increasing need for care; (3) life expectancy was limited; and (4) parents of a deceased child if death had occurred within the previous two years. The last criterion was chosen to obtain information about bereavement, which is an important domain of PPC. Parents had to be German-speaking and the child's age between 1 and 18 years. As a diversity of needs between diagnostic groups has been expected, we distinguished three diagnostic groups: (a) cancer, (b) neurological disorders, and (c) non-cancer/non-neurological conditions (e.g., heart diseases, or immunodeficiencies).

Attending physicians at the four hospitals contacted eligible families from each diagnostic group either during hospital visits or by telephone. We intended to interview five families per diagnostic group. All approached parents agreed to be interviewed and signed informed consent. The first author contacted the families and scheduled a time for the interview. Only one parent per couple was interviewed by the first author so as not to overburden the family caring for their severely ill child. Interviews were carried out from September 1, 2007 through January 31, 2008. The average length of the interviews was 90 min. The interview sessions were audiotaped.

Interview structure and data analysis

The interview guideline was designed on the basis of results from international studies and reviews [15, 23, 25, 26]. Parents were asked about main aspects of PPC services: communication with professionals, decision-making, coordination of care, support for family, and bereavement care. Questions addressed both the current care situation and parental recommendations for future PPC services; see also Table 1. The first author transcribed the interviews verbatim. Content analysis was used to derive themes from transcripts of the interviews [20]. The first author reviewed participants' responses in accordance with content analysis techniques and as a first step, phrased single units of responses. Similar units of responses were then grouped into thematic categories. All three authors developed labels for categories by reaching consensus through the process of rereading and discussion. In order to distinguish the three diagnostic groups, it was further investigated what categories were relevant for all three groups and what categories were brought up by participants from particular diagnostic groups. No quantitative analyzes were conducted, also due to the small sample size.

Results

Fifteen interviews were exclusively conducted with mothers. In two cases, fathers were present at home caring for the ill child. These two fathers listened to the conversation and occasionally contributed to the interview. Interviews took place at the location chosen by the mothers, either at home ($n=14$) or in the hospital ($n=1$).

Nine children received palliative care, and six children were deceased at the time of the interview. All children except two had at least one sibling. Thirteen of 15 children received PPC services at home. Table 2 shows the characteristics of the children in more detail. Similarities and differences in parental needs according to diagnostic groups are summarized in Table 3.

Parents' interaction with care team

Communication with healthcare providers Parents of children from all three diagnostic groups perceived honesty and openness from healthcare providers essential when delivering difficult news. Conversations about diagnosis or deterioration of the child's health status were highly stressful for parents, and they appreciated the attending physician's accessibility

Table 1 Interview guideline

Main topics	Interview questions
Introduction	Invitation to tell the interviewer about the child's story and the course of illness.
Communication with professionals	How did you experience the conversations with your attending physician? Which topics were discussed?
	Who was present besides the attending physician?
	Did you appreciate something especially?
	Was there something missing or what could be improved for future conversations with affected parents?
Decision-making process	How where decisions made? For example, concerning resuscitation?
	Who was involved in the decision-making process?
	To what extend was the child involved?
	Did you appreciate something especially?
	What could be improved for future decision-making processes?
Professional care of the child	Who did take care of your child at the hospital, e.g., nurses, physiotherapists?
	Who supported you caring for your child at home?
	Was there someone looking for your healthy child(ren)?
	What aspects of professional care were helpful to you?
	What needs concerning the care of your child were unmet?
Coordination of care	After talking about the professional care team, how was the care team organized or coordinated?
	Who was your constant contact person?
	Was there something missing or what could be improved for future coordination of care teams?
Financial aspects of care	How was the care of your child financed?
	To what extend were you informed about financial aspects of care by health care professionals?
	What aspects of financing were difficult to obtain?
Child well-being	What was important for your child to feel well according to the circumstances?
Support of the family	Who was involved in supporting your family?
	To what extent were your needs for support met?
	Was there something missing or what could be improved for future support for affected families?
Bereavement care	How were you prepared for the impending death of your child?
	Who provided support during the last days of your child's life?
	Who provided support for your family after your child's death?
	What kind of bereavement care did you need?
	Was there something missing or what could be improved for future bereavement care?

Table 2 Characteristics of children receiving pediatric palliative care services

Variable					Children receiving active care (n=9)	Deceased children (n=6)
Diagnosis						
Cancer					1	4
Neurological					4	1
Other (e.g. cardiac disease)					4	1
Age at the time of interview/death						
>	1	–	6	Years	5	2
>	6	–	12	Years	2	2
>	12	–	18	Years	2	2
Duration of illness						
>	1	–	12	Months	1	1
>	1	–	5	Years	5	3
>	5	–	10	Years	1	1
>	10	–	15	Years	2	1

Table 3 Similarities and differences in parental needs between diagnostic groups

	Similar needs
All three diagnostic groups	Open and honest communication from healthcare providers
	Expansion of support from home care nursing services
	Continued bereavement care by a former caregiver or by a person with experience in bereavement care and who had met the family while the child was alive
	Different needs
Cancer Group	Key worker to coordinate support by an interdisciplinary care team
Non-Cancer Group	Support at diagnosis of the illness by nurses or specialists (e.g. giving instructions of care) if parents lack the experience of a hospital stay
	Opportunity to contact a psychologist or social worker at diagnosis
	Opportunity to contact other families confronted with similar problems
	Active involvement of parents in the process of decision-making and respecting them as experts in taking care of their child

for answering further questions at any time. Parents also valued references to literature if available.

> My physician didn't embellish anything; he was honest about not being able to make a precise prognosis. I could ask all questions, they were answered by him. I asked how my daughter would die, and he told me that she would become more and more tired and fall 'asleep'. (Mother of a girl who died from brain tumor at the age of 5)

Decision-making and parental involvement Parents of children with neurological, metabolic, or heart diseases reported recurrently that they had to struggle to obtain more individually adapted care for their child—that is, concerning aspects of nutrition, personal hygiene, or the administration of medications. These children could not always communicate their needs directly, and parents saw themselves as their advocates. Parents appreciated it when healthcare providers respected them as experts in taking care of their child and actively involved them in decision-making processes.

> As a mother, I had to fight over and over for my daughter, when nurses took care of her and followed the usual patterns instead of regarding her particular needs. They gave her too much food, and she had a stomachache, but we were told to overlook it for ten days. It is very sad that a mother is not noticed in the hospital, since my daughter cannot express herself. (Mother of a 4-year-old girl suffering from a metabolic disorder, duration of illness 7 months)

Coordination of care Although parents of children with cancer benefited from the support of an interdisciplinary care team, they found it difficult to coordinate appointments and to keep in touch with professionals themselves. Besides the attending physician in the hospital or pediatrician at home responsible for medical issues, a "key worker" as defined by ACT (The Association for Children's Palliative Care) [1] was not available. Parents of children with cancer expressed their need for a constant and familiar contact person to coordinate the care.

> There was the whole care team, physicians, hospital and home care nurses, psychologist, and social worker; [...] it was somewhat complicated, because so many people were involved. We coordinated it ourselves. We could reach all these people, because I always asked, "Is there something else that can be done for our daughter?" (Mother of a girl who died from neuroblastoma at the age of 6)

Professional home care Thirteen children received PPC services at home during at least one phase of their illness. In Switzerland, home care nurses (Kinder-Spitex; in Zurich called "kispex") provide home care for children and adolescents. These organizations are organized and financed by the cantons and municipalities. Parents across all the three diagnostic groups highly valued the home care and support provided by these home care nurses, which in some cases went on for several years. Parents relied on home care services in order to cope with the requirements of daily care. Health care providers such as pediatricians, home care nurses, or physiotherapists visiting families at home often became persons of trust for parents.

> Today, I have "kispex"; this is my resource. With this service my life changed. My daughter was six years old at that time. Without "kispex" this would not have been possible. I have people on this team who know [name of the child] for years. (Mother of a 15-year-old girl with a neurological disorder from birth)

In Switzerland, children's hospice programs similar to institutions in the UK or in Germany do not exist. Therefore, we asked parents about their thoughts on the idea of offering children's hospice services in form of a separate facility and if they thought they could benefit from a hospice house as a respite from daily care at home. Most parents had already heard about children's hospices in Germany from newspapers or television, but parents from all three diagnostic groups stated that they preferred taking care of their child at home. In order to recover from the strain of daily care, parents wanted more support from the home care nursing services (kispex). Parents reported that kispex would allow them to spend some time with their healthy children or together as a couple with the assurance that their ill child was at home in a familiar environment, being cared for by familiar nurses.

> I myself prefer having the nurses from "kispex" come to my home more often instead of going somewhere else with him [ill child]. (Mother of a 5-year-old boy with a metabolic disorder; duration of illness two years and 10 months)

Support for the family

Parents' perception of support at diagnosis One of the most striking differences between the diagnostic groups was the perception of support at the beginning of the child's illness, when parents first learned of their child's life-limiting disease. Parents of children with diseases other than cancer reported feelings of tremendous loneliness and helplessness after being told the diagnosis by their attending physician. They knew the name of their child's disease but not what to expect in the near future. Parents were mostly sent home with their child. Without the experience of a hospital stay, parents missed out on instructions given by nurses or specialists and on contacts with other families confronted with similar problems.

> We got the diagnosis, but afterwards we felt abandoned; nobody was there to help us. We had a dying child; we went home and were alone. No one else had the same disease. (Mother of a 9-year-old boy with a neurological disorder; duration of illness 2 years)

Professional psychosocial support Another important difference between the diagnostic groups pertained to a more structural issue, the provision of professional psychological and social support for families with children suffering from neurological, metabolic, and cardiac diseases or immunodeficiencies. As attending physicians, oncologists usually arranged a first meeting for parents with a psycho-oncologist and social worker in the hospital. Families of children with other life-limiting diseases lacked this kind of professionally established support. These parents expressed a wish to be referred to or to be contacted by a psychologist and social worker following diagnosis. Over the course of the disease, parents would have liked to develop a relationship to a psychologist or social worker who was familiar with the child. Parents would have sought advice from a psychologist, for example advice on how to inform siblings about their severely ill brother or sister who would probably die soon.

> There was no psychologist contacting me and offering support. That was what I wished to happen—someone from the hospital coming to me and someone available I could contact later on, who was with us from the beginning. (Mother of a 4-year-old girl with a neurological disorder from birth)

Bereavement care

Immediately after the child's death, parents from all three diagnostic groups described bereavement care as intensive—that is, they received condolence letters or telephone calls from physicians, nurses, psychologists, or social workers. Parents greatly appreciated healthcare providers attending the funeral. However, parents of all three diagnostic groups reported that adapting to daily life without taking care of their ill child was a struggle. With the loss of their child, parents' regular contact with healthcare providers, home care nurses or hospital staff, lessened over time or broke off suddenly. These parents lost important others who had witnessed their exceptional situation and on whom they could no longer rely.

> I lost my daily routine; you lose your child and almost your social network as well. I spent almost more time with them [kispex] than with my husband or friends. (Mother of a girl who died from neuroblastoma at the age of 6)

Parents also reported a desire for a continuing bereavement care. Such care would not necessarily have to be provided by a former caregiver but by a person with experience in bereavement care and ideally by someone who had met the family while the child was alive.

Discussion

Parents caring for their child with a life-limiting condition had overall needs, such as open and honest communication with healthcare providers, promotion of home care services, and long-term bereavement care. The provision of hospice services did not emerge as a solution of high priority. There were differences between diagnostic groups regarding inter-

disciplinary care approach, coordination of care, and psychosocial support from the beginning of the illness (Table 3).

Parents from the three diagnostic groups agreed on the importance of open and honest communication by healthcare providers, especially when being given difficult or bad news. Access to staff members, particularly to the attending physician, as well as written information was highly valued by parents. These findings are consistent with previous studies [2, 19, 22, 27]. Receiving clear information about what to expect during end-of-life care and healthcare providers delivering news with empathy are considered to improve the quality of care [2, 19]. Parents with access to staff members not only gain information but also reassurance and trust [21]. Written information is highly valued, as it can be read repeatedly, as needed [25].

All parents greatly appreciated the home care services provided by the Swiss Kinder-Spitex association. Other studies confirmed parental preference for caring for their child at home as a place of "normality" [27], where the family acts as a protective system [8, 23]. While care at designated hospice houses is common in other countries, particularly for the provision of respite care, parents in this study seldom expressed the desire for a children's hospice outside the home. Parents' preference for home-based respite care can be attributed to the well-established home care services in Switzerland and to the rather absent institution-based respite care in Switzerland.

There was also agreement among parents concerning bereavement care. An ongoing bereavement follow-up would be appreciated. Parents described intensive contacts to hospital staff or home care nurses immediately after the child's death, whereas over time, these contacts decreased significantly. Consistent with previous studies [3, 9, 21, 22], regular contact to healthcare providers served as primary social support for parents, and they experienced the lack of contact after the child's death as an additional loss. Contact after the child's death by healthcare providers, such as visiting the family at home, may be beneficial for parents, as has been noted in other studies [4, 12]. Continuing and ongoing bereavement care, as the parents in this study recommended, could be provided by a person who is already known to the family and is experienced in the field of bereavement care and grief counseling.

It is remarkable that all participants were grateful for the opportunity to tell their stories. They saw a personal benefit in making their child's illness meaningful for others by sharing their knowledge and experience.

Interview responses distinctly revealed differences in parental needs depending on the diagnostic group, mainly between parents of children with cancer and parents of children with neurological, metabolic, and cardiac diseases or immunodeficiencies. Parents of children with life-limiting diseases other than cancer reported unmet needs related to practical support for care at the onset of illness, availability of professional psychosocial support, and involvement in decision-making processes. Empirical studies addressing parental needs of children with life-limiting diseases other than cancer have described problems related to being left alone with worries, having difficulty in finding information about the child's disease, financial support, and managing everyday caregiving [5, 13, 24]. To overcome one of these difficulties, parents expressed a need for practical support right at the beginning of the illness, when struggling to adapt to the new and demanding situation.

The inclusion of parents in decision-making processes is another important concern of parents. It has been shown that healthcare providers, acknowledging parents' responsibility and contributions to the child's care, preserve the integrity of the parent–child relationship and help parents to cope with the loss of control during hospitalization [21, 22].

Parents of children with cancer expressed a strong need for improved coordination of care. Research has shown that the large number of health care professionals is problematic for parents when it comes to seeking clarification and orchestrating various services [8, 10]. It has therefore been proposed to assign a "key worker" who assists families in coordinating services and care [1].

There are several limitations to this study. First, although our findings provide insight into the PPC services of four children's hospitals, covering different regions of German-speaking Switzerland, the generalizability of our findings is limited due to the small sample size and the fact that interviews were conducted only in the German-speaking part of Switzerland. Second, since parents' needs were derived through qualitative analysis, the subjectivity of the researchers may have influenced the development of categories. Thus, reliability and validity of the interviews cannot be asserted. To address these issues and to evaluate interrater agreement, researchers have to participate in the coding process independently. However, the exploratory assessment we chose allowed to reveal bereaved parents' perspectives regarding PPC services in Switzerland and perceptions of parents with children receiving PPC. This combination may have provided a more accurate account of the current situation and reduced retrospective bias. Finally, interviews were conducted exclusively with mothers. This maternal dominance can be explained by the fact, that in most cases, mothers were the child's primary caregivers, and fathers had work obligations. Further research will need to address the fathers' views and experiences to generate a more complete picture of parents' experiences.

Keeping these limitations in mind, we believe that this study has important implications regarding the needs of parents also related to practical issues of care and the provision of services. In this context Switzerland may be an interesting country to study as PPC is rather undeveloped,

and concomitantly it may be compared with other European countries, such as Germany or the UK that already provide a much broader spectrum of PPC services. So, the perspectives and experiences of families who receive or have received some kind of care and the question about their priorities of what would be needed and how PPC services should be designed and developed if started from the ground seem to be of high relevance.

This needs analysis sheds light on the unique needs of parents caring for their child with a life-limiting condition in Switzerland. Parents of children with life-limiting diseases other than cancer need professional psychosocial support starting at diagnosis and continuing throughout the course of illness, irrespective of acute crises. Hence, the provision of psychosocial support represents an important element of care in general and would lead to improvement of future PPC services for children with any life-limiting disease. Furthermore, the coordination of health care professionals from different disciplines remains a difficulty; a key worker could assist parents with contacting the care team and orchestrate PPC services. A somewhat unexpected finding was that respite care in a children's hospice outside the home was not highly graded by parents of all diagnostic groups. However, a hospice-like institution might be a place for parents of children with neurological or metabolic diseases to become familiar with the specialized care for their child as well as to prevent social isolation especially at the time of diagnosis. This place could also play an important role for all families during their grief. Finally, the existing home care services (Swiss Kinder-Spitex association) need to be strengthened to ameliorate the situation of families with palliative care needs and their families in Switzerland.

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